The Infections Diseases Society of America (IDSA) has missed its target date of December 31, 2009 for a rewrite of the Lyme guidelines, which are being written by lead clinicians and handpicking “a likeminded panel, which met over a dozen times in 2009, is aiming to release recommendations as early as possible in the new year.” If a rewrite is called for, the IDSA revision would be completed in “several months to a year or more,” leaving suffering Lyme patients in treatment purgatory for four years since the scientific integrity of the guidelines was first questioned.

The reevaluation of the IDSA Lyme guidelines was driven by an antitrust investigation led by Connecticut Attorney General Richard Blumenthal. During his 17-month investigation, Blumenthal found substantial conflicts of interest among the guidelines’ 33 other medical societies, saying in a press release, “These organizations have a lot of influence over public policy, and people rely on their leadership. There’s evidence for disclosure and the accountability that results.”

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Between a broken health care system and biased medical guidelines that are still under development, Lyme patients are trapped by insurance companies to deny treatment. The Lyme disease community knows that conflicts of interest were a big issue in the Lyme vaccine. We also know that the narrow disease definitions that suited the vaccine trials the best, hurt patients by denying and delaying diagnosis to patients with Lyme.

At the July 30, 2009 Lyme evidence hearing, ILADs submitted 300 pages of analysis and 1,300 pages of peer-reviewed research contesting the IDSA Lyme Guidelines recommendations. Senator Grassley and CT Attorney General Blumenthal (who is now running for the Senate) will put some legislatures into making “non-profit” medical societies like the IDSA more accountable for patient welfare and less beholden to vaccine and drug manufacturers.

For an overview of the Lyme controversy, watch the UNDER OUR SKIN trailer: http://underourskin.com/watch.html. [Breaking news on this story as we went to press. Be sure to catch the next issue!].

More Delays in IDSA Lyme Disease Guidelines Revisions

By Kris Newby
www.underourskin.com

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Did this Little Woman have Lyme disease?

by M.M. Drymous

When Ian Graeves and Norm Horshchamb, experts in military poisoning, studied Alcott’s symptoms, they found that they didn’t add up. Alcott did not have the telltale signals for mercury poisoning or signs of terror in her handwriting. It seemed to them more like an immune system disorder. They suggested that, based upon her symptoms and a late portrait of her with a rash on her face, Louisa May Alcott suffered from a long immune illness, systemic lupus erythematosus. Another possible diagnosis that needs to be considered is Lyme disease. The late Dr. Paul Lavisie firmly believed that in some people, Lupa or Lupa-type syndrome was a reaction to an underlying Lyme infection. Modern patients suffering from chronic Lyme often exhibit the Alcott-like symptoms, and in some cases, a late portrait of Alcott showed the telltale signal that she had suffered from meningitis or a late portrait of her with a rash on her face.

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My father was a professional (although we remain uncertain of one of his earlier jobs when he was alive at the Chicago Fire Department in Chicago, Illinois in the early 1960s. When we were young I remember my father telling me that he was a bombardier at Camp Detrick instead of elsewhere such as Dugway Proving grounds. The Chicago Bridge and Iron Works received the contract to fabricate and deliver in 1949, a one-million liter test sphere which would be used for this purpose, called The Eight Ball. The sphere was completed in 1950 and cost three quarters of a million dollars, and weighted about 130 tons according to sources.

When I heard about a new film that was recently released called Under the Eight Ball, the name and the subject matter of Lyme disease spiked my interest. It begins with me familiar with the design of the sphere to my father and knew that he was involved, but not before exhibiting some very Lyme-like symptoms, I was curious to find out what to expect except for the "biowarfare" angle and of course to see if I entered my preview with a curi- 

nous, open mind.

Directed by Timothy Grey Hall and Breanne Russell, with Justin Blake as producer, this film has certainly grabbed your attention immediately with its edgy music and non- 

conformity story opens with the chronologic story of Tim’s sister, award-winning investigative journalist Lori Hall-Steere, who is visibly sick and dealing with an illness with "unknown origin." While Lori remembers having been bitten in Florida by a spider when visiting downtown near Detroit, by the time she returns to her hometown City, she had a halmark Lyme “ball”-eye rash and symptoms including muscle pain.

Following this, Lori experienced cold and flu-like symptoms, and although she suspected Lyme disease, she was repeatedly told an incredulous statement made by the medical team. She is told, “there is no Lyme in Michigan.” A menu of diseases followed, and finally, Guillain-Barré syndrome, MS, Lupus, Lyme and ALS. Some of Lori’s symptoms continued to return and she was treated for Lyme disease as well as Ehrlichia and reinfections that physicians who can be fatal by itself.

After a fairly rapid progres- sion of those nine months, Lori was put on a merry-go-round of antibiotics, steroids and non-prescriptive agents that appear to have made her condition far worse and led to the topic of decision making and requiring a venting. All along, the words “Lyme disease” seem to fall on deaf ears while a neuro- 

ologist told her "incredibly cold hands and feet." Although I am not a violent person, hearing those words caused me to react and reach into the film and grab the medical staff by the shoulders and yell, “This is Lyme disease, that is her voice, “there is no Lyme in Michigan.” A menu of diseases followed, and finally, Guillain-Barré syndrome, MS, Lupus, Lyme and ALS. Some of Lori’s symptoms continued to return and she was treated for Lyme disease as well as Ehrlichia and reinfections that physicians who can be fatal by itself.

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Shattered Dreams?

by Linnette R. Mullin

"Perseverance is not a particular distinct grace of itself, but such a virtue as crowns all virtue; it is such a grace as casts a general beauty and glory upon every grace; it is a grace that leads every grace on to perfection."

~ Thomas Brooks 1608-1680

We all have our dreams made of? Are your desires God’s desire? One Sunday my pastor spoke God's answer to my questions of His will for me. He said, “God will for you to obey Him.” I struck a simple statement, I yet found it profound. It isn’t a question of whether or not to become a missionary, or to sing in the choir, or teach a children’s class, or any other ministry. It’s a matter of standing in tune with God and obeying His word. The first step in obedience loving God and faith in Christ alone: "If you want your foot to come afterward and I was so disappointed. But, I have to submit to His provi-" I was very disappointed. But, I dience being love for God and the fever to come afterward and I was so disappointed. But, I didn’t know if I would be up to it. I sent in my registra- ment and money, hoping that I coon, or our plans and goals. I was so disappointed. But, I dience being love for God and faith in Christ alone: matter of standing in tune with God and obeying His word. The first step in obedience loving God and faith in Christ alone: "If you want your foot to come afterward and I was so disappointed. But, I didn’t know if I would be up to it. I sent in my registra- tion and money, hoping that I coon, or our plans and goals. I was so disappointed. But, I didn’t know if I would be up to it. I sent in my registra- 

"Many are the plans in the mind of a man, but it is the purpose of the LORD that will stand.” Proverbs 19:21 (ESV) I admit that sometimes I half and puff over this verse, usually when there’s something I feel I just have to do or some-thing I really want to do. But, most of the time it brings me comfort. As Judy pointed out, it’s comforting to know that while my body, my circum-" many are the plans in the mind of a man, but it is the purpose of the LORD that will stand.” Proverbs 19:21 (ESV) I admit that sometimes I half and puff over this verse, usually when there’s something I feel I just have to do or some-thing I really want to do. But, most of the time it brings me comfort. As Judy pointed out, it’s comforting to know that while my body, my circum-

"The Lord is with us as we stand with the pieces of our shattered dreams. He is our strength, as well as our sanctity. Without Him, all hope would be false if not non- existent."

~ By Les Roberts

"The Poison Plum is a gripping, chilling novel exposing the rampaging epidemic of Lyme disease now sweeping across America and the disease’s connection, if any, to the government’s top-secret biological research laboratory at Plum Island, New York. www.poisonplum.com You can order the book online at the website!

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God Makes All Things Beautiful in its Time...

by Linnette R. Mullin

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God Makes All Things Beautiful in its Time...
The Cost of Compassion

by Joan Vetter

At this time, all eyes and ears are on the terrible crisis in Haiti. How do we live a life of godly compassion for the earthquake victims in Haiti as well as other situations? Let’s ask Jesus by going to the scripture where He reveals His heart of compassion and use that for an example of what He expects of His followers.

First, as Jesus was preaching, teaching and healing every sickness and every disease among the people, He saw the multitudes and He was moved with COMPASSION for them because they were weary and heavy-laden, like sheep having no shepherd. Then He said to His disciples, (who walk together) “The harvest truly is plentiful, but the laborers are few. Therefore pray the Lord of the harvest to send out laborers into His harvest.” (Matthew 9:36-38). Thus, first of all we can surely pray for laborers to minister both to the spiritual needs of the people in Haiti as well as the physical needs. Most of us can’t go ourselves, but we can donate our resources to an organization we trust.

Of course we are told in James 2:15-16 that if a brother or sister is naked and destitute of daily food we’re not to just say, “God bless you, but we are to give them what they need. It’s so easy to rationalize this and say we can’t help the whole world and just choose not to do anything. However, the Lord guides us by His Holy Spirit to show us specifically where we are to give. We can full well find a ditch on either side - either feeling overwhelmed and constantly convinced that we are not doing enough or hardening our hearts and failing to recognize who we are to reach out to.

Another place where we learn of the compassion of Jesus is in Matthew 18:21-35 where Peter asked Jesus how often should he forgive someone one. He told the story of a king who was settling accounts with his servants. One owed him a large amount of money. Since he was not able to pay off the master, the master commanded that he be sold, but he fell down before him and cried out for the Master to have patience with him. His master was moved with COMPASSION, and forgave his debt. But that’s not enough; someone who owed him far less, demanding violently that he pay up. When the Master discovered this, he called him a wicked servant, reminding him that he should have shown COMPASSION even to the Master who showed him COMPASSION.

In Luke 7:13 Jesus meets a widow who has gone to bury her only son. We are told the Lord had COMPASSION upon her and raised her son from the dead. This is not something that happens very often, but it does happen. One of my favorite stories in the Bible is 2 Cor. 12:9-10. We are told of a father with two sons. One demanded his inheritance and took off. His father spent his money ended up feeding pigs. Something of a great way off, you can be high if your illness is not at least believed to exist. But if you still want a relationship; it’s a healthy one in other ways, it can happen.

The odds are that, in time, your friend will eventually have his own health crisis and have some level of having standing about what you have faced on a daily basis. He may even turn to you for advice. Be supportive and encouraging. Don’t say “I told you so.” Get over it. Get over with it.

Relationships with those who are suffering from a chronic illness can be high if your illness is not at least believed to exist. But if you still want a relationship; it’s a healthy one in other ways, it can happen.

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The Lyme Disease Bacterium: Nothing is Simple

Part 2 in a series

by Dr. Jon Sterngold, M.D.

The bacterial cause of Lyme disease is called Borrelia burgdorferi, named after Willy Burgdorfer PhD, the researcher who first identified this germ in 1982. This spirochete, a corkscrew-shaped bacterium, is unique in the known bacterial realm because of the quantity of extra DNA it carries that enables it to evade detection and attack from our immune system. It can change its outer protein coat, thus cloaking itself from immune detection. It also can completely change form, becoming a treatment-resistant cyst or by totally shedding its outer coat and entering our own cells. The bacteria that generally live in the interior of those cells are found in various tissues, and they move around inside them. Most of the common bacterial diseases we hear about in medicine are from bugs that reproduce in less than 24 hours. When antibiotics ‘hit’ the reproductive or active metabolic machinery of these germs, they grow and thrive. They are reduced to the stature of ‘little’ themselves because their on-going energy production cycle as short as a day but can completely change form, that the Lyme bacterium eventually takes up residence, in some cases in which the Lyme disease has been treated - long with always long-term, high-dose antibiotics. Tests to determine whether someone has Lyme disease are very problematic. The common tests measure levels of antibodies we make that are specific to the Lyme bacteria. But, if the bacteria can hide, change form, immunologically ‘cloak’ itself, and can suppress our ability to make antibodies, a person quite ill with Lyme can have totally negative tests. What commonly occurs is that after a year or so of antibiotic use, which can render some of the bacteria into the immune system can recognize, the tests turn positive. The dilemma is that when someone is looking for a diagnosis, an answer to profound suffering, a physician who relies on initial test results might call it wrong and the patient will have no answer and no effective treatment. This is part of what defines the differ- ence between ‘lime literate’ MDs who understand the prob- lems with testing and treatment challenges versus non-Lyme lit- erate physicians who, for some very compelling reasons, can’t or won’t manage this disease. The range and depth of this problem is immense and will be discussed in the next article to follow.

2010 Needs a Fearless Conversation About Vaccines

by Barbara Loe Fisher

As the second decade of the 21st century begins, it is clear that the first one saw big changes in the way we think about health and vaccina- tion. A good example is the fact that the majority of Americans “just said no” to getting an H1N1 influenza shot last year. The truth is, most of us just didn’t buy the hype about swine flu. Perhaps it is because we are tired of constantly living in fear. The Decade of Fear Fear was the unifying emo- tion of the previous two decades but which was not as long as about nine months. During a phase of prolonged inactivity, it is very hard to kill. These are some of the reasons that an established Lyme infec- tion can have to fall down, too. Such fun! “Ring around a rosie” is a class of illness called autoim- mune, helping them to thrive. They tend to die, though they sometimes do. It is a parasitic existence. In addition to symptoms that stem from inflammation of the brain, nerves, heart, blood vessels, joints, and connective tissue, which the Lyme bacteria cause through multiple mecha- nisms, we also know that the disease can induce another class of illness called autoim- mune disease. Maladies such lupus, multiple sclerosis, and Lou Gehrig’s disease (ALS) can actually be caused by Lyme disease. These diseases are not considered to be curable, but there are many cases in which the autoimmune disease resolves completely when the Lyme disease has been treated - always with long-term, high-dose antibiotics. Tests to determine whether someone has Lyme disease are very problematic. The common tests measure lev- els of antibodies we make that are specific to the Lyme bacte- ria. But, if the bacteria can hide, change form, immunologically ‘cloak’ itself, and can suppress our ability to make antibodies, a person quite ill with Lyme can have totally negative tests. What commonly occurs is that after a year or so of antibiotic use, which can render some of the bacteria into the immune system can recognize, the tests turn positive. The dilemma is that when someone is looking for a diagnosis, an answer to profound suffering, a physician who relies on initial test results might call it wrong and the patient will have no answer and no effective treatment. This is part of what defines the differ- ence between ‘lime literate’ MDs who understand the prob- lems with testing and treatment challenges versus non-Lyme lit- erate physicians who, for some very compelling reasons, can’t or won’t manage this disease. The range and depth of this problem is immense and will be discussed in the next article to follow.

MEDICAL PERSPECTIVES

 Around A Rosy

by Virginia T. Sherr, M.D.

First image is that of small children at play. If they are adults involved in the game, they are reduced to the stature of “little” themselves because they have to fall down, too. Such fun! “Ring around a Rosy” is beloved by toddlers because it can be a great equal- izer with adults. There is noth- ing authoritarian about a singing adult dropping on the grass. This playfulness has a grim history, however. It seems to have originated during the Great Plagues that swept across Europe during the Dark Ages. The “falling down” at the end had to do with the fact that peo- ple were killed by the hundreds of thousands, and the “rosy” is said to refer to the way that people tried to protect them- selves with flowers, an old-time herbal remedy, perhaps. Today, the grass upon which children play harbors potential for two differ- ent kinds of “rings”: the telltale rings in the rosy red grass and brush wherever ticks are found. However, state and local Departments of Health, government officials, and most public health officials from across the country are beginning to find a collective voice to demand action - after September 11, 2001 - after a smallpox scare. However, state and local Departments of Health, government officials, and most public health officials from across the country are beginning to find a collective voice to demand action. In the coming years, the public will demand vaccines or drugs used dur- ing a government declared pub- lic health emergencies. For three years after 9- 11, special interest lobbyists invoked bioterrorism and fear of infectious microorganisms to follow the Homeland Security Act. Unprecedented Executive Branch Power And within weeks of 9- 11, a Congress driven by fear quickly passed The Patriot Act to empower the Homeland Security Act. Unprecedented authority was given to the Executive branch of our gov- ernment, including creation of the third largest federal agency - the Department of Homeland Security. And then public health officials pushed for passage of new Model State Emergency Health Powers Acts to expand the scope of action that can be taken by health officials whenever a pub- lic health emergency is declared. Pharma and Public Officials Push Agendas For three years after 9- 11, special interest lobbyists invoked bioterrorism and fear of infectious microorganisms to follow the Homeland Security Act. Unprecedented authority was given to the Executive branch of our gov- ernment, including creation of the third largest federal agency - the Department of Homeland Security. And then public health officials pushed for passage of new Model State Emergency Health Powers Acts to expand the scope of action that can be taken by health officials whenever a pub- lic health emergency is declared. Pharma and Public Officials Push Agendas For three years after 9- 11, special interest lobbyists invoked bioterrorism and fear of infectious microorganisms to follow the Homeland Security Act. Unprecedented authority was given to the Executive branch of our gov- ernment, including creation of the third largest federal agency - the Department of Homeland Security. And then public health officials pushed for passage of new Model State Emergency Health Powers Acts to expand the scope of action that can be taken by health officials whenever a pub- lic health emergency is declared.
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National Multiple Sclerosis Association: www.nmss.org

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Colorado Mary Parker 303-447-1602 milehightick@yahoo.com Connecticut www.timeoflyme.org 914-738-2358 Meetings: first Thursday of every month from 7-8:30 p.m. at the Greenwich Town Hall National Support: truthaboutlymedisease.com/ Dana Floyd, director LDA of Iowa PO Box 86, Story City, IA 515-432-3628 ticktick2@micahi.com Kansas 913-438-LYME Lymefight@aol.com Montana bcpickthorn@earthlink.net North Carolina Stephanie Tindall sttindall@yahoo.com South Carolina Contact Kathleen at (864) 704-2352 greenvillelyme@bellsouth.net

Texas Lyme Disease Association

Lyme Disease Support New Mexico Veronica Medina (505)459-9858 vmedina@comcast.net Oklahoma Janet Stephanie 405-399-0401 janci@LDSGorg www.LDSG.org Portland, Oregon Meets 2nd Sunday of each month 2010 NW 22nd Street Second Floor from 1:3 PM 303-590-2528

TEXAS : Greater Austin Area Lyme Council - Teresa Jones tmomintexas2@yahoo.com Dallas/Ft Worth John Quinn Jquinncdjr.org 214-749-2845 Houston Contact: Teresa Lucher lucher@globalnet.org League City/ClearLake & IASA Area Sandra Mannelli smannelli@comcast.net Washington State Alaska Beverly Rocks WA-Lyme-owner@ yahoogroups.com TX/ IL/ MN Regional areas Contact PJ Langhoff (920) 349-3853 www.Sewill.org www.Lymecleague.com (Intl)

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eariscorman@aol.com

Dallas - Fort Worth Lyme Support Group

Monthly Meetings:
2nd Saturday each month 2-4 p.m.

Harris Methodist Hospital- HEB
1600 Hospital Parkway
Bedford, TX 76022-6913
We meet in the left wing when facing the front of the building.

Contact our group leaders for more information:

Rick Houle, email: Pedler3710@aol.com
Home: 972.263.6158 or Cell: 214.957.7107

John Quinn
jquinn@dart.org
Conflicted Lymie

by Jennifer Allton
http://jmgarnet76.blogspot.com

Most people wouldn’t even realize that I have Lyme Disease unless I told them. It is hard for them to fathom that a PICC line was sustaining my life a year ago. My life appears normal in 2010. God helped me when the quality of life a year ago. My life was null of fun and normality. He gave me the strength to put one foot in front of the other to not only fight for myself, but for others with Lyme Disease. He put people in my path that had a hand in my current state of wellness and for that I am so thankful. In the past year, conflicting emotions run through me as God has finally given me a seemingly ordinary life. Ever feel conflicted? What’s conflicting about that you ask? I find that I am not quite normal and I am not quite a Lymie. I’m in Lyme limbo so to speak. This time of wellness is difficult because most of my friends were in Lyme treatment well before I started treatment and they are still very sick. Some of them are even sicker now than they were then. They call me lucky, blessed and normal. I feel lucky and blessed, but I definitely do not feel normal.

I feel like my body is the game of Jenga. We’re taking pieces from the base and adding them to the top. Each part we pull may or may not be a load-bearing piece. If the wrong component is pulled, I fear that my body will just come crashing down. It is very important to be careful with every single piece and use caution with every move. My inner soul is aching because I don’t feel part of my most inner circle anymore. Even though it is probably not true, I think that my Lyme friends feel as if I can’t understand what they are going through because I am well.

On the other hand, it is hard to live a normal life because I have lived the Lyme life for so long. There was a point in 2008 where I was at my doctor’s office nearly every day. I was getting IV’s, picking up supplements, picking up IV things for home or having an office visit. There are still remanents from that time in my home. I still have an IV pole, specialized PICC line dressings, even the PICC line itself, heparin and saline solutions.

The list of what I have from that time in my life goes on and on. Sometimes I just want to throw it all away or give it to others that need it, but then I want reminders of just how far I have come. I need to know how abnormal I was to know how normal I am now.

The other conflicting role is that I became proficient at hiding my physical pains and ailments. I became so good at adapting that sometimes these ailments are hidden from even me. When I finally do complain, it is a bit about a pain here or there, I get a lecture from my friends about how I need to be in back in treatment. I immediately think hateful thoughts towards the spiral bacteria that ruined my life. Then approximately ten seconds later, I pick myself up by the bootstraps. I finally have an immune system and my body is finally doing what it needs to do.

But I still feel conflicted. I am a Lymie that can’t be normal and feels somewhat ousted by the Lyme community since I am not complaining about ailments I do have. The “normal” don’t desire me to be around when I do complain about my weaknesses and those with Lyme Disease don’t want me because I am somewhat normal. Yes, I know that this is all a falsehood created by my own imagination, but it feels somewhat true. Are there others that feel like this too?
PUBLIC HEALTH ALERT

Immune • Energy • Gut

Due to the efficacy and the science behind the products, these are my favorites - Joseph J. Burrasca Jr. M.D.

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